Managing Challenging Behaviors

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Our Goal Together

To Review:

• Challenging Behaviors in HD
• Psychiatric problems common in HD
• Provide helpful strategies for both patients and families
  – Behavioral techniques
  – Medication overview
In HD, Brain Changes Cause Behavioral Changes

• Psychiatric symptoms -- earliest and most disabling symptoms in the disease.

• When caregivers face these challenges, remember:
  – It’s the disease, not the person
  – The person with HD faces a series of losses. Frustration, anger, withdrawal can be the result of these losses.

• Understanding these concepts helps direct strategies
Chorea: involuntary movements

Symptoms in Huntington’s disease

- Impulsivity
- Balance problems
- Slow eye movements
- Episodic anger
- Irritability
- Slowness of movement
- Depression, anxiety
- Chorea: involuntary movements
- ↓ Multi-tasking
- Restless, fidgets
- ↓ Organizing
- Concentrating
- Prioritizing
- Fine motor tasks
- Trouble swallowing
- OCD
- Psychosis
Challenging behaviors

- Unawareness
- Impaired executive function
- Apathy
- Irritability and disproportionate anger
- Anxiety
- Obsessive thoughts and compulsive behaviors
- Depression and suicide
Unawareness
Unawareness

• This is hard-wired; not simply “denial.”

• Examples:
  – Failure to recognize the early symptoms of HD
  – Unawareness of decline in performance at home or work
  – Lack of recognition of need to stop driving

• Consequences:
  – Delays in diagnosis, failure to get help when needed
  – Job and personal losses
  – Externalization and blame of others
Unawareness Strategies

– **Confrontation often fails.** Don’t try to “inject” insight.

– **Seek help from medical team:** primary care physician, neurologist, SW, psychologist or psychiatrist

– **Seek help from outside agencies:** driver evaluation, job performance evaluation, case manager
Unawareness Strategies

Examples that may not work:

• “You have Huntington’s – you can’t drive.”
• “Your attention and motor skills aren’t sufficient for driving. We don’t want you or others to be hurt.”

– **Try**: “I’ll drive you – I was planning to go there today.”
– **Be selective**. Choose only important issues for intervention.
  • Identify the key issues that need intervention
  • Acceptance of other issues
Reduced Executive Function
What is Executive Functioning?

Speed of thinking, planning, prioritizing, organizing, concentration, decision making, flexibility, creativity

• Leads to changes in function, including reduced ability to carry out activities at work and at home
  – Poor performance at work, or work may appear sloppy, incomplete, or disorganized
  – Loss of initiation: can’t get started
  – Perseveration: getting stuck on certain ideas or activities
  – Lack of inhibition, inappropriate behavior, impulsiveness
  – Inability to recognize others’ emotions
  – Lack of recognition of hunger, thirst, even pain
Reduced executive function: Strategies

• **Behavioral techniques**
  - Rely on routines. Use calendars, schedules and lists
  - Break tasks down into small steps: one thing at a time
  - Simplify
  - Use prompts and cues
  - Offer choices rather than open-ended questions
    - **Example** “Would you rather have oatmeal or eggs?” instead of “What would you like for breakfast?”
  - Use short sentences with 1-2 pieces of information
Apathy
Apathy

- Loss of ability to start activities, often with loss of inner drive
- **Important brain circuits** involved in motivation, timing, switching from one activity or task to another **are damaged**
- **Apathy may be a feature of depression**, but many people with HD who suffer from apathy are **not** depressed
- Examples:
  - Getting out of bed
  - Completing household chores
  - Personal hygiene
  - Managing finances
  - No longer cares about things that used to be important
Apathy: Strategies

• Medical evaluation (rule out depression/metabolic problems)
• Behavioral strategies are the most successful
  – Simplify routines
  – Set up a daily schedule for wake-up and bedtimes, meals
  – Use a calendar for activities such as chores
    • Involve the person with HD in creating of the schedule!
  – Offer cues and prompts (phone alarms, verbal reminders)
  – Environmental stimulation: Adult Day Health Programs
• If apathy is severe, seek psychiatric care for possible use of stimulant medications
Irritability / Anger
Irritability and disproportionate anger

- Frustration / anger about loss of abilities is COMMON
- Loss of the ability to regulate emotions
  - The person with HD may lose their patience or tolerance for things that never used to bother them
  - They may find it difficult to shrug off minor irritations
  - There may be sudden, explosive anger episodes
- May also be a feature of depression

- Behaviors: screaming, swearing, threatening, slamming doors, hitting walls, pushing, striking or hurting others
Irritability and disproportionate anger

- **Behavioral strategies are most helpful**
  - Create a calm environment if possible
  - Set up daily schedule and weekly calendar
  - Identify anger triggers and avoid them
  - Use distraction, re-direction
  - **Practice de-escalation**: soft voice, respectful words, give space (including exit), don’t use touch, leave the scene
    - Safety is critical
    - Call authorities if necessary
Irritability / anger (continued)

• Reduce alcohol intake and eliminate recreational drugs

• Remove weapons from the home

• Identify and treat depression or anxiety

• If anger episodes are frequent, severe or don’t respond to the above, meet with neurologist or psychiatrist for medications
Anxiety: Strategies

• Create a calm environment
• Use schedules, calendars
• Simplify routines
• Allow plenty of time to complete daily tasks
• Counseling: cognitive-behavioral therapy
• Seek medical or psychiatric care for medications: SSRIs
Obsessive thoughts and compulsive behaviors

• **Obsessive thoughts**: recurrent, intrusive thoughts or impulses.
  – Concern with germs/contamination
  – Fixation on perceived past insults/injustices

• **Compulsive behaviors**: behaviors or routines which must be performed to reduce inner discomfort. Examples:
  – Compulsive exercise: walking 7 miles a day
  – Compulsive eating or drinking
  – Compulsive video-gaming

• **Strategies**:
  – Behavioral: structure the environment
  – Seek care from a neurologist or psychiatrist for medications
Depression in HD

- Very, very common!
- Thoughts of suicide may occur
  - Most commonly occurs around the time of diagnosis and early in the illness
  - Over 25% of patients with HD attempt suicide at some point in the illness.
  - Reported rates of completed suicide among individuals with Huntington’s disease range from 3-13%.
  - Treatment of depression with counseling, medications, and family and community support prevents suicide.
Managing depression

• Recognition is important

• Counseling: cognitive behavioral therapy may help

• Seek medical care for anti-depressant medications such as SSRIs

• For suicidal ideation, seek immediate help with crisis line, emergency department visit, or police if indicated
How common are these symptoms?

- Depression 20-60%
- Anxiety 35-60%
- Irritability 40-70%
- Apathy 35-75%
- Obsessions/compulsions 25-50%
- Psychosis 10%
Medications in HD

Goal:

Treat psychiatric / behavioral problems aggressively

We are very mindful of SIDE EFFECTS

--**good side effects** (sedation at night, appetite)
--**bad side effects** (worsening chorea, rigidity, confusion)
--drug—drug interactions
Medications in HD

- **Antidepressants** (Zoloft, Celexa, Effexor)
- **Antipsychotics** (Haldol, Zyprexa, Seroquel)
- **Mood stabilizers** (Depakote, Lithium)
- **Stimulant agents** (Ritalin)
- **Dementia medications** (Aricept, Namenda)
- **Dopamine depleters** (e.g. tetrabenazine)
- **Anti-glutamate agents** (e.g., amantadine)
Additional issues

• Distress at awaiting results of genetic testing

• Guilt at passing on autosomal dominant condition

• Coping with a progressive illness with midlife onset
Toolbox for managing challenging behaviors

• Understand the basis of the change in behavior
• Routines, routines, routines (simplify)
• Provide structure, prompts and cues
• Calm environment
• Regular medical care: physical and psychiatric
• Recognize danger signs
• Ask for help early. Share the care!
• HDSA website
Additional Important Points

• Help for family members, “caregiver distress”

• Reported higher rate of suicide in HD patients (combined risks of dementia and depression, family history of suicide in other HD patients)

• Availability of treatment / medications
Acknowledgements and Thank You

Patients and families affected by HD

Our Team: